

# Genetic screening: a comparative analysis of three recent reports

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## Abstract

*Three recent reports on genetic screening published in the United Kingdom, Denmark and the Netherlands are discussed. Comparison of the Dutch report with the Danish and the Nuffield reports reveals that the Dutch report focuses on the aim of enlarging the scope for action, emphasising protection of autonomy and self-determination of the screenee more than the other two reports. The three reports have in common that the main concern is with concrete issues such as stigmatisation, discrimination, protection of the private sphere and issues linked with labour and insurance. Some potential long term consequences, however, tend to be neglected or underestimated. These omissions are pointed out.*

In 1993 the Nuffield Council on Bioethics published a report, *Genetic Screening: Ethical Issues*,<sup>1</sup> which has already been reviewed in this journal.<sup>2</sup> Recently two other reports on genetic screening have been published in Europe, a report by the Dutch Health Council, *Genetische Screening* (1994),<sup>3</sup> and the report by the Danish Council of Ethics (1993), *Ethics and Mapping of the Human Genome*.<sup>4</sup> This paper, being part of a BIOMED project, EUROSCREEN I, compares and discusses the Nuffield report, the Dutch Health Council report and the Danish report.<sup>5</sup> The following aspects of genetic screening will be considered: aims and benefits of genetic screening; conditions to be screened for; perceived risks and harms; education; economic considerations; and the role of public authorities. Comparative analysis will be followed by a short discussion of some omissions.

## Stated aims and benefits

The Danish Council of Ethics, discussing genetic screening against the background of non-genetic screening programmes, notes that in screening the help-motive has changed. There is a shift from the

aim of treating, preventing and alleviating disease – an important goal of any screening programme – to the aim of offering the individual options. This second aim has become an important motive for genetic screening: help may mean offering information that enhances choice and scope for action.<sup>6,7</sup>

This goal is given much emphasis by the Dutch Health Council. In their report a major aim of genetic screening is to enable people to decide upon a course of action that is acceptable for them. This aim of helping people achieve greater autonomy in the sense of taking more control of their lives is hammered home throughout the report.<sup>8</sup> The shift from the aim of prevention and alleviation of suffering to enhancing autonomy comes out most clearly in the following passage: “Unless efficient therapeutic means are available to improve the quality of life of the person with the disorder, the purpose of screening lies especially in the use of the information for decisions about developing a relationship, reproduction, further development of life and determination of lifestyle” [authors’ translation].<sup>9</sup> The target clearly is the total life-situation of the individual, rather than the medical benefit.

This shift towards autonomy as an important target of screening is also apparent in the Nuffield report. Although the aim to improve the health of persons who suffer from genetic disorders seems to come first,<sup>10</sup> the report also points out that the benefits should be seen “as enabling individuals to take account of the information for their own lives and empowering prospective parents to make informed choices about having children”.<sup>11</sup> Alleviating anxiety is a third important aim,<sup>12</sup> which, however, is less emphasised in the Dutch and Danish reports.

Screening may contribute to achieving distributive justice if it is offered to everyone. This objective does not get much attention in the three reports. The Dutch Health Council remarks that a genetic test offered to all may advance equal access to health services, but an offer to a group with an increased risk can be justified. Criteria will be required then.<sup>13</sup> The Danish Council is also aware that screening gives many people a chance to gain a clear picture of potential disease. In their view screening is a

## Key words

Genetic screening; genetic counselling; public health policy; prenatal diagnosis.

community-based form of help based on the obligation to help the weak.<sup>14</sup> However, this theme is not dwelt upon. The Nuffield report does not discuss it.

## Condition

The Dutch Health Council leaves out of its guidelines the requirement that the condition screened for must be serious.<sup>15</sup> In an earlier report the health council said a restrictive list did not solve the indication problem. There they stressed that assessing the severity of a condition depended on personal factors, such as outlook on life and family size.<sup>16</sup> This view also seems to underlie the council's recent report: it is up to the individual and parents to determine whether a condition is serious enough to enter a screening programme. The Danish report also gives no specific guidelines concerning the severity of the condition to be screened for.<sup>17</sup> The Nuffield report does include the word serious in its requirements, but says that in the context of genetic screening it is difficult to define which disease can be considered serious, as perception of seriousness depends on treatment possibilities and may vary between societies.<sup>18</sup> Definition is also difficult because the severity of certain genetic disorders may vary greatly. This may be the reason why the three reports state that it is the individual who should eventually decide whether or not to participate in a genetic screening programme.

Screening for common diseases with a genetic component is foreseen in the three reports. In the Nuffield and the Dutch report the need for further study of benefits and disadvantages is stressed.<sup>19</sup>

## Perceived risks

An important normative determinant of genetic screening is the potential harm due to the introduction of screening programmes. This may be harm for the person screened or others (relatives, offspring, handicapped people and society). First we focus on the potential harm caused by offering a genetic screening programme, after that we will discuss potential harm connected with participation, disclosure procedures and use of information.

### RISKS CREATED BY AN OFFER

The Nuffield report remarks that genetic screening may bring anxiety for the individuals screened, but notes that it may have wider implications, especially for families.<sup>20</sup> According to the Danish report screening gives people a better idea of their risks, but the Danish council realises that an offer will threaten an individual's personal sphere and his/her right of autonomy and that consequences for other people must also be considered.<sup>21</sup> The Dutch report mainly focuses on the risks and harms for the individual screened: an invitation to undergo screening will confront people with risks of which they are not

(fully) aware and this may cause anxiety.<sup>22</sup> Anxiety may increase because there may be uncertainties about diagnosis and future development of the disease. An invitation to undergo screening may place people in situations of very difficult choices.<sup>23</sup>

### RISKS CREATED BY PARTICIPATION

The Dutch report discusses at length threats to individual autonomy and self-determination. Voluntary participation based on well-understood information is considered an absolute requirement for genetic screening and there must be safeguards for free individual choices during the whole screening process. Lack of adequate information may lead to misunderstandings and wrong decisions.<sup>24</sup> In order to avoid any influence on decisions to participate much attention should be given to the form and wording of written information about the screening programme. Furthermore there is a danger that a counsellor's personal views and motivation could exert pressure on the prospective participant. There is also the possibility of social pressure on the individual decision to participate.

Respect for autonomy also becomes manifest in concern for minors and the unborn: a disadvantage of genetic screening of minors is that it may threaten the future autonomy of the child as it can violate his/her right not-to-know.<sup>25</sup> With regard to the fetus, the Dutch report remarks that "in prenatal screening the right not-to-know of the expected child can be frustrated if parents decide to continue the pregnancy in case of a serious incurable late-onset disorder" [authors' translation].<sup>26</sup> However, the right of a fetus to live with a (serious) handicap is not discussed.

Voluntary participation might also be threatened because of possible social implications. The Dutch Health Council realises that a duty to report findings of genetic screening when applying for a job or when trying to get life or health insurance may lead to pressure on the individual and to decreasing interest in participation. Possible stigmatisation of participants may also influence compliance.<sup>27</sup>

The Nuffield report, as well as the Danish report, does not discuss threats to autonomy at such length. The Nuffield report states that compulsion must be ruled out,<sup>28</sup> and the Danish report remarks that a help offer should not intrude on the personal sphere and autonomy. Voluntariness, informed consent and confidentiality are important requirements<sup>29</sup> and both reports are aware that fears of discrimination (by increased premiums or exclusion) may discourage people from taking part in a genetic screening programme.<sup>30 31</sup>

### HARM CAUSED BY DISCLOSURE PROCEDURES

Screenees should be informed of the screening results and at present it is assumed that the information should be given non-directively. Also family members and relatives may be interested in disclosure of the

genetic information. Difficulties will arise if a screenee refuses to give consent to pass on the genetic information to relatives.

Much attention is given to protection of the autonomy and self-determination of the individual screened. The Dutch report emphasises that prospective participants in a genetic screening programme should choose an option that fits in with their personal views, but they also observe that guidance is important.<sup>32</sup> Counselling is considered especially important if the options are limited to termination of a pregnancy and the birth of a handicapped child. The council endorses professional advice and guidance.<sup>32</sup> Here the position of the council seems a bit ambiguous as it is not made clear what is meant by "guidance" and "advice", but it might be interpreted as a slight shift away from a very heavy emphasis on non-directive counseling in the 1989 health council report.

Non-directiveness in counselling at all stages of the screening process is also mentioned as an important requirement in the Danish and the Nuffield reports, but the Nuffield Council notes that in practice counselling is unlikely to remain completely neutral. In fact the council realises that a completely neutral stance may seem cold and unhelpful.<sup>33 34</sup>

Disclosure of screening results to others, notably family members, may be quite difficult. Although the Dutch report notes that screening results may have implications for others<sup>35</sup> and that this aspect should not be neglected when screening results are communicated, the Dutch Council does not discuss the implications of this. Instead, the council restricts itself to the observation that neither the influence of screening on relations with family members nor responsibilities concerning family, relatives and future children are clear. The council refers to the 1989 report for its stance on disclosure of information to others: consent of the person tested is needed for disclosure to relatives. If this consent is refused and if the screenee cannot be motivated to give consent the counsellor or physician is not allowed to disclose the information. The council admits this may occasionally lead to very difficult decisions on the part of the counsellor or physician who feels he has a duty to inform third parties to prevent serious harm to them. However, if they decide to disregard the refusal of consent, they should be able to justify their decision in court. On the whole this approach is very much on the side of individual autonomy and the protection of the personal sphere.<sup>36</sup>

Both the Danish and the Nuffield reports point out that genes are shared with relatives and that genetic screening can easily affect relatives of the persons screened.<sup>37 38</sup> The Nuffield report, however, discusses this at some length. Individuals screened should be made aware of the implications for their relations. Information may be vital to the well-being or future life of other family members and it may be

appropriate to treat those family members as a unit and "to place less emphasis on individual patient autonomy".<sup>39</sup> The Nuffield Council even suggests persuasion as a strategy to minimise potential harmful consequences to family members.

#### HARM CAUSED BY USE OF INFORMATION

The choices based on genetic information vary according to the sort of screening test offered and include options with regard to reproduction, selective abortion and changing of lifestyle. We will focus here mainly on reproductive choices. Attention will be given successively to the individual or the parents who have to make difficult choices, the unborn child with a detected genetic disorder, and social implications.

Carrier screening enables prospective parents to make informed choices about reproduction. One of the options is starting pregnancy in combination with antenatal diagnosis and subsequent selective abortion if the given disorder is detected. The Danish Council of Ethics notes that the question of abortion in connection with prenatal diagnosis will probably always be the subject of debate, but does not discuss the issue.<sup>40</sup> The Nuffield report says the decision to terminate a pregnancy may be agonising, and that guidance is needed, but does not really discuss the issue either. Instead, results of some pilot studies are presented, showing the degree of acceptability of termination of pregnancy.<sup>41</sup> Apparently both reports assume that the decision whether to have selective abortion after a positive test result is a matter for the individual parents. The Dutch report says the traumatic experience of termination of pregnancy should not be underestimated,<sup>42</sup> but stresses the free and informed choice of the persons screened: "It cannot be emphasised enough that genetic screening has the aim to enable people with a disposition for disorders in which hereditary factors largely determine the development of a disorder, in themselves or in their offspring, to escape their fate by giving them the freedom to make an informed choice to adopt a course of action that is acceptable to them" [authors' translation].<sup>42</sup> For the Dutch Health Council selective abortion is also a matter for the parents to decide and instead of consideration of moral aspects of selective abortion, this council too, presents data about acceptability of selective abortion in connection with certain hereditary diseases.<sup>43</sup> In disagreement with the recently introduced Population Screening Act, which does not regard selective abortion as a form of treatment or prevention, the council points out that selective abortion can be considered a relevant course of action in certain circumstances.<sup>44</sup>

Of course, it is not only the parents who are involved. Their decisions have implications for the unborn child, for example. However, the interests of the unborn child are not a matter for much discussion in the Dutch report, as it is apparently assumed that

the parents are responsible for the decisions they make regarding reproduction. The presupposition seems to be that it is in the interest of the child to be aborted in case of a disorder that leads to a short life with serious and degrading suffering. However, the difficulties of assessing the severity of a condition during pregnancy and the quality of life expected are not considered. The Nuffield report seems to hold the same view. Carrier and antenatal genetic screening offer an opportunity to avoid both a child born to suffering and the lifelong emotional cost to the rest of the family in caring for a child in such a condition. The position of the Danish Council of Ethics on this issue is not discussed.<sup>45</sup>

With regard to possible social implications, the Dutch report notes that termination of pregnancy because of a genetic disorder might lead to diminished acceptance of people with a handicap. This would be a disastrous development, and it would also "threaten the free choice of prospective parents in such difficult decisions".<sup>46</sup> It seems it is not so much the social implications that concern the council, but the pressure diminished acceptance of handicapped people may exert on individuals being screened. Freedom of choice is also threatened if inadequate care and attention is given to handicapped persons: lack of financial facilities to provide adequate services for the handicapped may lead to social pressure on the persons screened to choose the most advantageous option.<sup>47</sup>

Stigmatisation of persons and groups, with the possible consequence of more large-scale discrimination, is noted in all three reports. There are differences in the way these harms are assessed, however. The Danish report considers "branding" of handicapped people as utterly unacceptable. In the Nuffield report it is thought that proper educational programmes should reduce the risks of stigmatisation and discrimination.<sup>48</sup> The Nuffield Council also notes that the availability of prenatal screening, together with the termination of seriously affected pregnancies may reflect and reinforce negative attitudes of our societies towards those with disabilities. Interestingly, the Nuffield report points out an inconsistency: on the one hand there is a great effort to care for and integrate handicapped people in society, and on the other hand resources are also spent on preventing births of (severely) handicapped people.<sup>49</sup>

The Nuffield report is the only one which discusses the increasing risk of eugenic tendencies in society. The council realises that developments in genetic technology may lead to misuse for eugenic purposes, but the members of the council think this fear is unfounded, because the primary goal of genetic examinations and genetic screening is to help individuals and their families. Voluntary participation and better public understanding of human genetics are considered as safeguards to the threat of eugenic abuse. Emphasis on informed consent, confidentiality and central co-ordination

and monitoring of genetic programmes will also help in avoiding eugenic tendencies.<sup>50</sup>

## Education

With much emphasis on individual autonomy and free choice, informed consent is an important requirement in all three reports. Information is also needed for other purposes, however. In fact, education of the general public is considered an important strategy to solve several ethical problems.

The Dutch Health Council expects that large-scale genetic information will diminish the risk of stigmatisation.<sup>51</sup> Information will also bring adequate perception of and respect for handicapped people,<sup>52</sup> it will help people to assess their risks better,<sup>53</sup> it will diminish anxiety<sup>54</sup> and it will diminish regret in case of non-participation and the birth of a handicapped child.<sup>54</sup> Finally, education is thought to create solidarity with choices made by people screened.<sup>55</sup>

In the Nuffield report education is also seen as a major strategy for overcoming difficulties. Education is supposed to diminish misinterpretation, prejudice, stigmatisation and the danger of eugenics.<sup>56</sup> The Danish report notes the importance of education and suggests what sort of information should be included. Interestingly, both the Nuffield report and the Danish report suggest information about ethical aspects amongst the requirements,<sup>57 58</sup> whereas the Dutch report is silent on this.

It is remarkable that in spite of a stated reliance on "adequate" information, the Dutch report says that in fact little is known about psychological consequences of genetic screening. Also the effects on relatives and data generated about anxiety are unclear.<sup>59</sup> Lack of information about consequences for self-image and about how people are able to cope with the screening results is also noted and the need for more systematic research on the consequences of termination of pregnancy and consequences of screening for late-onset diseases is pointed out.<sup>60</sup> This suggests that proper education cannot be expected in the near future.

## Economic considerations

For the Danish Council screening is an expedient means of preventing costly treatment of disease, but it opposes the utilitarian approach suggested by the National (Danish) Board of Health's report, as it feels that this approach is not widely supported in Denmark.<sup>61</sup> The Nuffield report also states that benefits of genetic screening should not be calculated in purely financial terms, yet concludes at the end of the report that, in view of limited resources, resource costs and the relative priority of establishing a screening programme are factors that should be considered.<sup>62</sup>

The Dutch Health Council also recommends that no emphasis should be placed on cost-benefit analyses, as these may be a threat to individual decision-making – emphasising money savings as a benefit of genetic screening may lead to undesirable social pressure to participate in genetic screening programmes, compromising free choice.<sup>63</sup> There is no discussion of the costs of screening programmes in the context of limited health care resources.

### Role of public authorities

Except for the role of public authorities in connection with legislation for the use of genetic data and tests for employment, pension funds and insurance, there is little information about the role of public authorities concerning genetic screening within a health care context in the Danish report. The Nuffield Council suggests a central co-ordinating body that should undertake a review of genetic screening programmes. The Department of Health should take the lead in formulating detailed criteria for introducing genetic screening programmes into routine practice, says the report, and it should review genetic screening programmes and monitor their implementation and outcome.<sup>64</sup>

In the Dutch report we find the most extensive discussion about the role of public authorities: in the Netherlands genetic screening falls within the scope of the Population Screening Act of 1992 (enacted in 1996), which requires that the minister approve screening programmes before they are implemented, having been advised by the health council. A licence is refused if a screening programme is scientifically unsound, if it conflicts with the statutory regulations or if it involves risks for the prospective participants that outweigh the likely benefits. The rules for population screening to detect serious diseases or abnormalities which cannot be treated nor prevented should be very tight. It is realised that these requirements may create problems if genetic screening is concerned with reproductive decisions. The council is of the opinion that screening programmes which may be followed by prenatal diagnosis and selective abortion are acceptable. With regard to employment and insurance, the Dutch Council notes that self-regulation is not sufficient and that legislation will be required if new forms of uninsurability arise.<sup>65</sup>

### Discussion

Examination of the Dutch, Danish and Nuffield reports reveals great concern for autonomous decision-making, protection of the personal sphere and potentially harmful consequences of genetic screening for individuals. This is perhaps most clearly so in the Dutch report. In the Nuffield report, which seems to reflect most the attitudes of the medical profession, a greater consideration for the interests of others, notably family members and

relatives, is apparent. However, instead of summarising similarities and differences here once again, we may perhaps point at some omissions in the three reports.

1 There is some unclarity about the aims of genetic screening programmes in the three reports. Although they all point out that there may be important medical benefits, especially for treatable disorders, enhancement of autonomy and enlargement of scope of action has also become an important objective. Prevention or reduction of suffering are traditional goals of medical practice. Enhancing wellbeing by offering reassurance has also become common practice. This may make genetic screening for these purposes acceptable. Less clear is whether the enhancement of autonomy, as propagated especially in the Dutch report, should have such pride of place as an objective of medical practice. If autonomy is instrumental in the prevention of suffering of individual or family this goal seems defensible. If autonomy in the sense of giving people more control of their lives is the aim, the question of whether this is an acceptable aim of *medical* practice, especially if compared with other urgent health needs and limited health care resources, should be considered.

2 In genetic testing on request it is the individual who decides if a condition is serious in his or her particular situation. Can this approach also be used when introducing a large-scale genetic screening programme? The requirement in the English and Danish reports is that the condition to be screened for should be serious. In the Dutch report this is given less emphasis. It is unclear in this report who is to define a condition as being serious enough to justify the introduction of large-scale genetic testing. Is it the individual, the medical profession, the community, or a combination of these – or is it a private company, which will simply put a genetic test on the market for financial benefits?<sup>66</sup> It is also unclear what criteria will be used to establish the severity of a disease. If, as seems likely, it becomes increasingly easy in the future to screen for desirable and undesirable traits, and for severe and mild genetically based diseases and susceptibilities, we may well be in need of further criteria or guidelines. These may perhaps not only be in the interest of a future child (in the case of prenatal screening), but they also seem important for health and life insurance and the funding or reimbursement of genetic tests and screening programmes.

3 In the reports selective abortion is presented as an acceptable way of preventing suffering. Although it seems difficult to prohibit an individual or couple from having an abortion for genetic reasons if the law permits abortion on request, the question should perhaps be considered whether by offering genetic screening programmes for untreatable diseases at a

population level selective abortion is not institutionalised as an accepted form of medical practice. Institutionalisation may bring the danger of setting quality standards for acceptable and unacceptable forms of human life.

4 A tendency is noticeable, more so in the Dutch and English reports, to fall back on pilot studies which provide statistical material about compliance numbers, acceptability for the target group and willingness to terminate a pregnancy in case of an affected fetus. Here a consumer-oriented approach becomes apparent: if a sufficient number of people seem interested a screening programme can be introduced. In combination with an approach that favours individual autonomy there may be a danger that neither moral reasoning nor carefully developed criteria or guidelines, but the market, will decide whether a genetic screening programme will be introduced. In that case it will be difficult to control potentially harmful long term consequences, such as slowly changing attitudes towards reproduction or a growing demand for optimum quality babies. It is a problem the President's Commission for the Study of Ethical Problems in Medicine and Biomedical

Research notes: "The choices made by many independent individuals form new societal norms that are not the conscious creation of any one person. These in turn may not only impose significant limitations on people's choices in the future but may also alter basic societal attitudes and presumptions".<sup>67</sup> The Nuffield report notes a potential for eugenic misuse,<sup>68</sup> but is confident that genetic education will greatly reduce this danger. However, it is perhaps not the government policy prescribing minimum standards of quality of life which is a threat, but eugenic tendencies growing from below. Without further criteria regarding the conditions to be screened for, but with increasing possibilities for commercial genetic screening and testing in a society where the consumer decides what is acceptable, an increasing number of parents may start thinking in terms of minimum standards of quality of life for their future children. Hard evidence for this cannot yet be provided as we may be only at the very beginning of such a development. We believe such a development to be not wholly hypothetical, especially in a society where abortion on demand is a possibility and where persons with health problems tend to be seen as interfering with efficiency and profit.

*Table Summary of points of agreement and differences*

	<i>Danish Council of Ethics</i>	<i>Nuffield report</i>	<i>Dutch Health Council</i>
Aims/benefits	Emphasis on individual health benefits Enhancement of choice	Emphasis on individual health benefits Enhancement of choice	Emphasis on enhancement of choice Medical benefits
Condition	Health problem Guidelines difficult	Serious health problem Guidelines difficult	Health problem Individual decides
Perceived risks			
Offer	Threat to personal sphere and autonomy Implications for other persons	Creates anxiety Implications for families	Creates dilemmas Creates anxiety
Participation	Individual/social pressure Social implications may reduce participation Intrusion of personal sphere	Individual/social pressure Social implications may reduce participation	Individual/social pressure Social implications may limit participation Misinterpretation of information
Disclosure	Directiveness	Directiveness, but non-directiveness potentially unhelpful	Directiveness
Disclosure relatives	Refusal to pass on genetic information Conflict of interests	Refusal to pass on information Conflict of interests Mild persuasion recommended	Refusal to pass on information Conflict of interest Emphasis on protection of private sphere
Use of genetic information	Discrimination Stigmatisation	Discrimination Stigmatisation Diminished acceptance of handicapped people	Discrimination Stigmatisation Diminished acceptance of handicapped people threatens free choice
Reproductive decisions	Abortion issue not discussed	Difficult decisions: guidance needed	Difficult choice: parents decide
Education	Adequate informed consent needed	Adequate informed consent needed Prevention/reduction of potential harmful social consequences	Adequate informed consent needed Prevention/reduction of potential harmful social consequences Little information on psychological and social consequences
Economic considerations	Financial benefits do not have priority No discussion of commercialisation of genetic screening	Financial benefits do not have priority No discussion of commercialisation of genetic screening	Financial benefits not major consideration No discussion of commercialisation of genetic screening
Role of public authorities	Government control to manage social consequences	Coordinating body formulating criteria	Population Screening Act in force. Legislation needed to control social consequences

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- 2 Gillon R. Ethics of genetic screening: the first report of the Nuffield Council on Bioethics [editorial: a personal view]. *Journal of Medical Ethics* 1994; 20: 67-8, 92.
- 3 Shapiro D. Debate: the ethics of genetic screening: the first report of the Nuffield Council on Bioethics: another personal view. *Journal of Medical Ethics* 1994; 20: 185-187.
- 4 Uzych L. Genetic screening and ethics [letter]. *Journal of Medical Ethics* 1996; 2: 53-4.
- 5 Gezondheidsraad. Commissie screening erfelijke en aangeboren aandoeningen. *Genetische screening*. Den Haag: Gezondheidsraad, 1994; publikatie nr 1994/22. This publication has a 9-page summary in English (22-31).
- 6 Danish Council of Ethics. *Ethics and mapping of the human genome*. Copenhagen: Danish Council of Ethics, 1993.
- 7 EUROSREEN I is a three-year multi-national project on genetic screening, funded under the European BIOMED programme, and focusing on ethical and philosophical perspectives of genetic screening. One objective is to review and analyse reports on genetic screening published in various European countries. A recent report published in the US by the Institute of Medicine: Andrews LB *et al*, eds. *Assessing genetic risks: implications for health and social policy*, Washington 1994, has not been included in this comparative analysis.
- 8 See reference 4: 53.
- 9 See reference 4: 63.
- 10 See reference 3: 49, 58, 66, 69, 75, 77, 79, 93, 96, 98, 103.
- 11 See reference 3: 69.
- 12 See reference 1: 5, 17.
- 13 See reference 1: 80.
- 14 See reference 1: 17.
- 15 See reference 3: 72, 79.
- 16 See reference 4: 52, 63.
- 17 See reference 3: 102.
- 18 Health Council of the Netherlands. *Heredity: science and society*. The Hague: Health Council of the Netherlands, 1989: 79-80.
- 19 See reference 4: 58.
- 20 See reference 1: 17, 18.
- 21 See references 1:16-7; 3:76-7
- 22 See reference 1: 3, 5.
- 23 See reference 4: 52-4, 57.
- 24 See reference 3: 71, 73.
- 25 See reference 3: 36, 54, 71.
- 26 See reference 3: 36, 54, 55, 61, 68-9, 77, 103.
- 27 See reference 3: 53, 78.
- 28 See reference 3: 78.
- 29 See reference 3: 69, 98.
- 30 See reference 1: 4.
- 31 See reference 4: 52, 53.
- 32 See reference 1: 69, 71, 72.
- 33 See reference 4: 79-82.
- 34 See reference 3: 75.
- 35 See reference 4: 66.
- 36 See reference 1: 37.
- 37 See reference 3: 35, 61.
- 38 See reference 16: 90-7.
- 39 See reference 4: 61-2.
- 40 See reference 1: 37, 42, 43.
- 41 See reference 1: 43.
- 42 See reference 4: 59.
- 43 See reference 1: 5, 23, 26.
- 44 See reference 3: 96.
- 45 See reference 3: 64.
- 46 See reference 3: 86.
- 47 The council refers to an earlier report: Danish Council of Ethics. *Fetal diagnosis and ethics*. Copenhagen: Danish Council of Ethics, 1991. This report is not considered here.
- 48 See reference 3: 37.
- 49 See reference 3: 96.
- 50 See reference 1: 77-9.
- 51 See reference 1: 77.
- 52 See reference 1: 80-81.
- 53 See reference 3: 69.
- 54 See reference 3: 61.
- 55 See reference 3: 62.
- 56 See reference 3: 63, 69.
- 57 See reference 3: 81.
- 58 See reference 1: 75-81.
- 59 See reference 1: 36.
- 60 See reference 4: 66.
- 61 See reference 3: 57, 59, 61, 63.
- 62 See reference 3: 65, 67-8, 72.
- 63 See reference 4: 50, 51, 64.
- 64 See reference 4: 80, 87.
- 65 See reference 3: 96.
- 66 See reference 1: 83-85.
- 67 See reference 3: 83-90, summarised in English on 28-9.
- 68 All three reports are silent on the issue of commercialisation of genetic screening and testing. This is remarkable as the first genetic tests have already been put on the market. It is expected that in the near future commercial genetic testing will be possible for many diseases with a genetic component. As this is a reason for concern it is being thoroughly examined as part of the Biomed EUROSREEN II programme.
- 69 President's Commission for the Study of Ethical Problems in Medicine and Biomedical Research. *Screening and counselling for genetic conditions: the ethical, social and legal implications of genetic screening, counseling and education programs*. Washington DC: US Government Printing Office, 1983: 53.
- 70 See reference 1: 81.